

GAO

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Obtaining Care for Chronically Ill Children in  
the Home Based Setting

Statement of  
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Before the  
Committee on Finance  
United States Senate



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## Obtaining Care for Chronically Ill Children in the Home Based Setting

### Summary of GAO Testimony

About 1 million children are thought to be seriously chronically ill. Some of them are cared for in the home and community based setting. GAO reviewed the experiences faced by families in obtaining medical and other support care for their children in this setting, with the objective of identifying significant barriers.

The need for medical and support services at home varies considerably by type of service. Of the families that needed services, nearly half of them had difficulty obtaining one or more services, particularly support services such as day care, baby sitting, and respite care. The importance of these types of services was a common theme expressed by parents.

Our work to date indicates that the access problems for these services are primarily related to inadequate information at the time of discharge from a hospital and a lack of financing.

One way of easing the access difficulties and making the transition from hospital to home easier is through more, and clearly defined, case management services. This would include the preparation of a written home care plan and the designation of a case manager at the time of discharge.

Mr. Chairman and Members of the Committee:

I am pleased to have the opportunity to summarize our review of the barriers to home and community based care for seriously chronically ill children. It is estimated that about 1 million children fall into this category. You asked us to review the experiences faced by families in obtaining medical and other support care for them, with the objective of identifying barriers to obtaining care. Our study focused on 10 medical conditions covered in a 1985 study of childhood diseases at Vanderbilt University. These were

Juvenile-Onset Diabetes	Leukemia
End-stage Renal Disease	Asthma
Spina Bifida	Cleft Lip and Palate
Congenital Heart Disease	Sickle Cell Anemia
Cystic Fibrosis	Muscular Dystrophy

According to the Vanderbilt study, an examination focusing on families with children having these conditions would provide a good indicator of the costs and problems parents face in obtaining home care for a wide variety of chronic illnesses.

We have completed about half of our planned work. We visited children's hospitals and public and private providers in five localities (Dallas, Atlanta, Los Angeles, and Cincinnati, and the District of Columbia and adjacent Prince George's County in Maryland). We also received questionnaire responses from 197 families with seriously chronically ill children in these localities and held focus group interviews with 40 parents. Our observations today are based on this work. We plan to visit nine more localities during the next 2 months.

#### Families Require Wide Range of Medical and Support Services

Our questionnaire survey shows that parents of seriously chronically ill children require a wide range of medical and support services. All but two families who returned the survey said they used 1 or more of 14 services identified as being important to children and families in the home or community setting. Parents indicated that medical services were required more often than support services. The medical services required most frequently were doctor office visits and medications. The support services required most frequently were baby sitting, counseling, day care, and transportation.

### Obtaining Needed Services Can Be Difficult

Although over half of the families reported they were able to obtain all services they felt they needed, the remainder reported difficulty obtaining one or more of the services. The most frequently needed medical services were not difficult to obtain. However, doctor home visits, seen as needed by only a few parents, were difficult to obtain by over half of them.

Support services seemed to present greater difficulties. Many parents experienced problems obtaining two or more of them. Unlike medical services, the frequently needed support services, day care and baby sitting, were difficult to obtain.

Perhaps most informative were our focus group discussions with 40 parents and interviews with parent support groups. These tended to center on problems in obtaining support services for the family rather than on medical care for the child. Parents told us they had difficulty finding providers of day care, respite care, and baby sitting who would serve chronically ill children. When parents found providers, the services were sometimes too expensive for families to obtain. The importance of these types of services, as well as the need for family counseling to deal with the trauma of having and caring for a seriously chronically ill child, was a common theme expressed by these parents.

### Inadequate Information and Financing

Our work indicates that the access problems for both medical and support services are primarily related to inadequate information at the time of discharge from a hospital and a lack of financing. As you know, children's hospitals have discharge planning processes and provide written home care plans to help the parent and the child with the transition from the hospital to the home. Our work in several hospitals shows these processes and plans tend to focus on the medical care needed by the child and usually do not address the support services needed by the family.

Parents told us that hospital discharge planning was good in preparing them to meet the health care needs of children at home. They were often told about the medical needs of the child and were provided with training and written instructions addressing medication types and frequencies, the need for and frequency of therapies, and needed equipment and supplies. But some parents told us that they did not receive enough information on medical service providers or how the services could be financed. Many more parents said that they were not provided information on the availability of support services. They said that because there was no central source of information on providers and services, they had to go through an extensive search process before they either found providers or learned that the services were not available. Among the sources parents used to obtain information about services

and providers were telephone directories, other parents, and support groups.

Parents also told us they needed help particularly during the child's first weeks at home. Parents said the transition to the home environment would have been easier if someone had made follow-up visits during the first week after discharge and helped them obtain needed medical and support services. A case manager, who could make the transition from hospital to home easier, was seldom provided.

In the financing area, the lack of public financing and/or private insurance for some medical and support services needed in the home environment was of primary concern to parents. On the medical side, parents said they experienced problems obtaining reimbursement for certain medications and therapies. Also, insurance copayments mounted up quickly and became a financial burden for some families. However, the child's medical needs were generally met.

Paying for support services and special items needed to keep the child at home was more of a problem because these items are often not covered by public financing and private insurance. Examples frequently cited were day care, baby sitting, and certain special medical items, such as the nutritional needs and vitamin supplements for diabetic children.

#### Easing the Access Problems

Our work suggests that greater use of case management could ease the access problems caused by inadequate information about service availability. The Department of Health and Human Services' task force report on technology-dependent children contains a definition of case management that applies to the broader population of seriously chronically ill children. It provides for a single service coordinator--the case manager--and, among other things, addresses the need for medical and support service information, planning, and coordination. Providing a case manager would be a positive step in helping parents obtain needed services, especially in the child's first weeks at home. The case manager could furnish information on both medical and support services in the community and possible funding sources, and participate in the development of the written home care plan.

Many children with the 10 medical conditions we studied are treated in children's hospitals. These hospitals seem to be the logical place to lay out a complete plan for the child's transition home and identify someone to help carry out the plan.